Disability Visibility Podcast

Episode 42: Employment

Guests: Rooshey Hasnain and Kate Caldwell

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast

Introduction

[radio static and hip-hop]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Hello, my friend! This is the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. Welcome our first episode in 2019! Woo hoo!

Today's episode is about is employment. A lot of attention is paid on the employment rates of people with disabilities and why hiring disabled people makes good business sense. We're gonna focus on some specific issues and hear from two professors from the University of Illinois at Chicago about their research. First, Rooshey Hasnain will talk about a recent pilot project in partnership with the Illinois Division of Rehabilitation Services called ADOPT, which stands for Asians with Disabilities Outreach Project Think-Tank). Next, Kate Caldwell tells me about her research on disabled entrepreneurs with a project called CEED, C-E-E-D, which stands for Chicagoland Entrepreneurship Education for People with Disabilities project. We're gonna discuss barriers, underrepresentation, structural issues, the need for research and much more. Are you ready? [electronic beeping] Away we go!

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

Introduction to Rooshey Hasnain

ALICE: So, Rooshey, thank you so much for being on my podcast today. Would you like to introduce yourself?

ROOSHEY HASNAIN: Thank you for this opportunity. So, my name is Rooshey Hasnain. I'm a Clinical Assistant Professor and also the Principle Investigator on a current project called PRIDE—Partners of Refugees in Illinois Disability Employment—and was also the Principle Investigator for a project called ADOPT: Asians with Disabilities Outreach Project Think-Tank. I'm affiliated with the University of Illinois at Chicago. And I'm with the Department of Disability and Human Development, and I'm also affiliated with the Rehabilitation Sciences Program.

[bright piano music]

ADOPT: Asians with Disabilities Outreach Project Think-Tank

The ADOPT Project started in 2010. We were so fortunate to be given the opportunity thanks to President Obama's administration's American Recovery and Reinvestment Act of 2009 that created new jobs and new opportunities across all industries. We were looking at issues related to Asian Americans living with disability here in Illinois and to see how we can support job-

seeking Asian Americans with disabilities to access Vocational Rehabilitation supports and ultimately desired employment goals.

This is a project that really grew from grassroot organizing and spending time in various pan-Asian-American communities having conversations with community leaders, certainly with self-advocates, with family members, developing relationships with community-based organizations throughout the state of Illinois. And particularly in the greater Chicago/Cook County area, we have non-profit organizations that are managed and run by Asians and Asian Americans who are focusing on social justice issues or issue-based agendas that allowed us to start conversations around what disability is in the community, what it means in the community.

We also, of course, partnered with various disability organizations as well. The funding really came through the Division of Rehabilitation Services, which is part of the Illinois Department of Health and Human Services trying to understand what the needs are around individuals living with a condition that may link to what we mean by disability or chronic health conditions or mental health conditions and to look at which communities tend to be underserved or under-represented. Those relationships really have continued long-term in different ways. What drove the project to existence was that we came to realize that only less than 1% of the client population within the state Vocational Rehabilitation system in Illinois represented Asian/Asian-American individuals.

ALICE: Wow.

ROOSHEY: That's very, very low. We wanted to understand: why is there such an under-representation of the Asian/Asian-American community?

ALICE: Do you mind describing that agency?

ROOSHEY: The Division of Rehabilitation Services sits within DHS, which is the Department of Health Services here in Illinois. We worked specifically with the Division of Vocational Rehabilitation, the system that supports people with disabilities who are interested and motivated in pursuing employment opportunities. The DRS/VR system is set up to provide various kinds of supports and services to support an individual's path into an employment situation. There's a very extensive navigation of getting a referral, opening a case, where a counselor works very closely with a jobseeker. There's various evaluations and opportunities to explore what kinds of workforce opportunities might be a fit for them in terms of preferences and skillsets and interests.

ALICE: It's often an entry point for a lot of people who are new to work or just starting get the tools and supports they need to either go to school or just start working. It is a major agency that a lot of people with disabilities utilize across the country.

[bright piano music break]

Research about why Asian Americans in Illinois are underserved by VR

ALICE: So, based on your research, what are some of the reasons why Asian Americans in Illinois are so underserved by the state VR system?

ROOSHEY: We found that certainly there's a lack of awareness about what is DRS and VR? What is the purpose of it? And so, many individuals just were not exposed to this as a resource. But we were also exposed to individuals who had been connected to VR and had better experiences.

It also comes down to how disability is viewed. We found that disability may not necessarily equate in different languages to the same kind of meaning that's used here in this country. The notion of disability or person with disability—person-first language—very important element that has been introduced in this country. But the word "disability" is a very difficult word to translate into the hundreds of languages and dialects that are spoken.

ALICE: And the idea itself may not even exist within some cultures or might be a different idea that's analogous but not exact.

ROOSHEY: Absolutely. Absolutely. And you know, in my own language, there's sort of this misrepresentation of disability because it skews more towards a deficit, right, or a weakness. It all depends on how a person may relate to it. ADOPT was trying to expand the opportunity to improve access and to look at how stigma plays a role in pan-Asian communities. 'Cause we found that even having the conversations when we first started and continue to have these conversations in the community to understand, well, what do you mean by "disability?" And what do you mean by access to leadership positions or access to services and supports like DRS/VR in terms of education?

But it's beyond education. It's beyond training that we discovered in our ADOPT initiative through focus groups, through one-to-one interviews, through the mapping of the incredible diversity and assets of the pan-Asian community that exists here in Illinois. Showing that diversity was very important for us as we were working closely with the Division of Rehabilitation Services. The ARR funding that I mentioned earlier through President Obama's administration, the funding actually came through DHS and DRS. So, they're very visionary in thinking about well, how can we do a better job in outreach, in not only Asian Americans but other under-served community groups? So, although ADOPT was charged to focus on Asians and Asian Americans to understanding that 1% representation and how we could shift that, we found that we were actually supporting and expanding a wider multicultural reach to other individuals of other groups. Which is very natural if you think about the communities that we live in.

[upbeat piano and guitar music break]

ADOPT's recommendations for changes VR can make and improved outcomes

ALICE: So, what were the recommendations that ADOPT made in terms of specific, systemic changes that the Department of Vocational Rehabilitation could really implement to really improve the way they do outreach and the way that they serve Asian Americans and other minority groups better?

ROOSHEY: Certainly, we were intentional about the importance of working with the community and to build that trust. The three very important areas of focus that the ADOPT project took, one was to build the capacity of pan-Asian community non-profit organizations to become more aware of how to become more inclusive of clients and staff that are living with disability. The second was how we can actually create language and linguistic supports within very large, important support systems like state Vocational Rehabilitation systems. ADOPT did a language access survey, the first of its kind, with the state VR system to see how people who are limited English proficient, how they access services. Because we found that that was another barrier. And that's not only language access spoken, but that's also in addition to sign language. And the third was how we can actually connect with employers and build partnerships in order to expand and enhance employment opportunities. It resulted in community organizations—Asian-American serving non-profit organizations—who actually became VR community-based providers and continue to be community-based providers to do case management to address

cultural and linguistic diverse preferences to increase that 1% so that more individuals are accessing the system. We developed a sustainable service delivery model, the first of its kind: a non-traditional Vocational Rehabilitation within a traditional Vocational Rehabilitation system.

ALICE: That's so important because sustainability is the real key to really building structural changes. I'm assuming it ended a few years ago. Is that correct?

ROOSHEY: Yes. Due to funding cuts that the state of Illinois faced, we were one of the projects that actually was cut. But the vision of the project continues through other important projects such as PRIDE.

ALICE: I am curious about whether the outcomes have improved for Asian Americans being served in the DRS/VR system.

ROOSHEY: Certainly there's been an increase from that 1%. The number of referrals that were coming into DRS has continued to increase, and the placement of individuals into employment opportunities has improved substantially for a diversity of individuals who come from Asian backgrounds and other backgrounds.

ALICE: That's wonderful.

[upbeat piano and clapping hands music break]

Other areas to investigate

ALICE: Regarding Asian Americans with disabilities and employment or economic self-sufficiency, what do you think are some areas that you haven't worked on yet that you feel like we still need to investigate?

ROOSHEY: I would like to continue focusing on innovative solutions that are culturally appropriate, given that the employment situation for people with disabilities remains to be improved. It would be really wonderful to see if there could be a way to really bring this to a national level and across different states. It's not necessarily only economic enhancement for an individual and his or her family, but it's actually economic enhancement for neighborhoods, for cities, for the state, for individuals to engage in whatever mechanism that allow for workforce development, right?

I think the other piece that I would like to emphasize is how we can recognize that language differences and cultural differences are assets. So, certainly ADOPT is one example of a model that looked at workforce advancement in partnership with Asians and Asian Americans with and without disabilities and important role that community-based organizations across different sectors and the importance of working with allies and champions in communities to continue the solution-seeking elements that we need to continue.

ALICE: Absolutely. It takes a village.

ROOSHEY: It takes a village. It does.

ALICE: Thank you so much!

[pensive piano music break]

Introduction to Kate Caldwell

ALICE: Kate, thank you so much for being on my podcast today. I was wondering if you wouldn't mind introducing yourself.

KATE CALDWELL: Thank you so much for inviting me. It's my pleasure to be here. So, my name's Kate Caldwell, and I'm a Clinical Assistant Professor in Disability and Human Development at the University of Illinois at Chicago. I identify as having multiple invisible disabilities. I've been starting small businesses ever since I was a child. I started a cartoon company for lunch money. I started a greeting card company for my friends, graphic design in high school.

I work on a interdisciplinary project. It was intended to bring two fields together that had never worked together before: Disability Studies and Entrepreneurship Studies. We did that by doing a bunch of focus groups with social entrepreneurs with disabilities and by interviewing experts working in the field. A lot of the reasons why people are looking at entrepreneurship as a potential employment strategy is because you can shape your job and your business around your interests as well as your needs.

When you look at disability employment policy, they're what's called the "necessity-based policies." Whereas when you look at all entrepreneurship policy, they're what's called "opportunity-based policies." Entrepreneurs with disabilities usually aren't being well-served by either system because they don't just need needs-based policy; they also need opportunity. Entrepreneurs with disabilities should be benefitting from both the disability service system and the business service system. Our research has actually found that they're not utilizing either.

[mellow keyboard music break]

Barriers people with disabilities face to starting their own businesses

ALICE: What do you think are some of the structural and social barriers that people with disabilities face when starting their own businesses?

KATE: They experience financial and economic barriers. So, for example, an entrepreneur with a disability may not have a work history or a traditional work history. They may not have a credit history. They may not have assets. If they're using benefits, they may not have a savings account or a credit account.

ALICE: When I think of entrepreneurs, I immediately think about immigrants and communities of color. And I am curious about whether you got a sense if there were many that were, let's say, immigrants or non-English speakers? Because it's so hard to break into the job market and because within their own communities, there are these informal networks of supporting each other financially.

KATE: The way that entrepreneurship's been used in other disadvantaged communities like ethnic minorities, like immigrant groups, like women as well, and LGBT groups is that it's been intended to help people get out of poverty by allowing them to become financially self-sustainable as well as create jobs in their communities through entrepreneurship.

A lot of times, people use the term "self-employment" and "entrepreneurship" interchangeably. And they're actually very distinct. So, self-employment refers to an individual that is starting their own business with the goal of becoming financially self-sustaining, whereas entrepreneurship is different is because the goal's actually to create profit. And in order for that business to create

profit, then they're probably gonna need to hire at least one more employee as that business grows. You're not just creating one job for yourself, and you're gonna be more likely to hire people from your community. And that's why it's an anti-poverty strategy, because it's more of an exponential growth.

Social entrepreneurs, commercial entrepreneurs, and statistics on self-employed people with disabilities

ALICE: Earlier, you mentioned the term "social entrepreneurs," and what is the difference between that and a regular entrepreneur?

KATE: Social entrepreneurship is distinct from commercial entrepreneurship in that it's where someone's starting a business that has a social mission at the center of it. And usually, this is because they see a problem in their community or an unmet need that they wanna address by starting a business. So, we don't actually have statistics for it, but it's very likely that people with disabilities are going to start social enterprises because the market need that they see is something that they experience personally on a regular basis.

ALICE: You know, I am curious about whether there are any existing statistics about the number of entrepreneurs with disabilities in Illinois or nationally.

KATE: Yeah. So, when we look at the statistics that we have for entrepreneurship, we don't really have that many. What we do have is what's called, in VR, "case closure in self-employment" when people are starting their business. We're just capturing that data point of entering into starting a business. Sometimes it's entrepreneurship, but we don't know how many of those are actual entrepreneurs. And we don't have data after that entry point, right? And that number's actually very, very low. When you look at the national current population statistics data, we actually have another reference point, and that's self-employment among the disability population. The number's much higher than we're seeing in VR. So, in VR, it'll be about maybe 3% a year are closing in self-employment, maybe. However, when we look at VR, the number's been as high as 11.6% of people with disabilities were self-employed. It might not seem that high, but, it's about 6% in the general population.

And so, the other thing is that when you look at the data that we have on how many people are starting the process of starting a business, the number of nascent entrepreneurs is about four percentage points higher than the number of people in the general population who are in self-employment. If we take all that information together, we can project that the rate of people with disabilities who are nascent entrepreneurs is probably almost 15%. That's a huge number of jobs that can be created if we're supporting those people in starting, in growing their businesses if we're helping those entrepreneurs with disabilities make their first disability hire.

ALICE: And you mentioned that you did focus groups with people with disabilities who are social entrepreneurs, but was there a reason why you didn't do focus groups with people with commercial enterprises?

KATE: A lot of people were using the term "social entrepreneurship" for businesses that weren't necessarily social enterprises. There are some organizations out there that are using the term "social entrepreneurship" to try and repackage sheltered workshop arrangements or other arrangements where they aren't necessarily paying their employees with disabilities and that this is very problematic. Whereas actual social entrepreneurs with disabilities are really doing amazing things and have a lot of potential to contribute to our society, the economy, their

communities. And so, for me, I really wanted to see what social entrepreneurs were doing versus the other arrangements.

ALICE: Great.

[lounge-y music break]

What data do you most want to collect?

ALICE: And if you had a magic wand and could collect any sort of statistics or data that would really advance your research and advance policy, what kind of data would you love to get your hands on?

KATE: There's something called the Panel Study of Entrepreneurial Dynamics, otherwise known as the PSED. And they say, "Do you have a disability that would prevent you from working?" Well, the way you phrase it, no one's gonna say yes and actually respond to the rest of the questions in that survey. I think 150 out of the thousands and thousands in this longitudinal panel study actually answered that question, "Yes, I have a disability." What I would love to do is to actually include disability in that panel study more effectively.

Another thing is that we need to reevaluate our outcome indicators for entrepreneurship. We're not collecting data on it partly because we don't know what data to collect. And so, we need to look at what outcomes and indicators are actually gonna get us an accurate picture of how people with disabilities are participating in entrepreneurship at various points throughout the process.

Top things learned from entrepreneurs with disabilities' stories

ALICE: Tell me about some of the top things you learned from actual entrepreneurs who are sharing their story with you.

KATE: I did my dissertation on social entrepreneurs with intellectual disabilities specifically, and one thing that struck me about those interviews is that entrepreneurs with intellectual disabilities don't necessarily want to tell you about the barriers they're experiencing. Like, they want you to feel that they can be business people, that they can run their own business, that they know what they're doing. And yet the rest of the interview, they would talk about a lot of the barriers they were experiencing, but they didn't wanna frame it as barriers.

Another thing that came up a lot was really just wanting people to get out of their way and let them do what they wanna do, right? So, in general, they know what they wanna do. They need help and resources and support in order to do that, just like any other business person, right? And so, when we talk about entrepreneurship for people with disabilities, for some reason, there's this idea that oh, they have to do it by themselves, you know. That's just setting them up for failure.

And then the last thing that I think really jumped out at me was that one of the main barriers facing entrepreneurs with disabilities is sorta this fear about if their business makes too much of a profit, they're worried that they might lose their Social Security, might lose their Medicaid. And so, one thing that a lot of entrepreneurs with disabilities do is they limit their success. They keep their business small so that it doesn't threaten their benefits. But it's very difficult to be successful while keeping your business from growing.

ALICE: You know, it is a benefits poverty trap. It's almost a rigged game where people are set up to not really reach their potential.

KATE: There's some things in benefits planning specifically for entrepreneurs with disabilities that can help bridge that gap, but not enough people know about it, and it's not offered enough.

I've been trying to help inform policymakers about the research evidence and about what entrepreneurship looks like in the disability community so that when they're creating policy and policy recommendations, they can really create effective ones that are actually gonna make a good change. And I was actually on a national task force for employability and workforce development for people with disabilities on the sub-committee for entrepreneurship, tax incentives, and procurement. And we came up with some really good recommendations that you can find in this Work Matters report coming out of the National Conference of State Legislators and Council of State Governments.

One of the very first recommendations is for existing systems—so, Vocational Rehabilitation in particular—to recognize that entrepreneurship is a form of competitive, integrated employment, especially in those states that've adopted employment-first policies. Everyone should have the opportunity to become an entrepreneur if they want to, to pursue it if they want to, based on their own merits and not just because they have a disability or not.

ALICE: Great. Thank you so much.

[chill jazzy music break]

The CEED Project: Chicagoland Entrepreneurship Education for people with Disabilities

ALICE: Earlier, you mentioned the CEED Project, Chicagoland Entrepreneurship Education for people with Disabilities. I was wondering, what is the current status of the CEED Project?

KATE: Currently, the CEED Project is kind of on hiatus. But when we did our earlier research, we found that people with disabilities didn't have equal access to entrepreneurship education and training opportunities in the same way that other folks did. And also, service providers working with them didn't necessarily know how to do that job, Disability Community Agencies or DCAs providing employment services and supports to people with disabilities. From the business side of things, we have Small Business Development Centers that are funded through state and federal funds and are intended to provide business services and supports to entrepreneurs who are starting businesses, and it's all free, right? And because it's federally- and state-funded, they're required under the Americans with Disabilities Act to be accessible to people with disabilities.

And when you talk to the Small Business Development Centers, they'll say, "We aren't necessarily seeing a lot of people with disabilities asking for our services." And when you talk to entrepreneurs with disabilities, you'll hear a lot of, "Well, you know, they weren't necessarily accessible." Disability services providers know the disability end of things, but they don't understand the business development part. And Small Business Development Centers, they know the business part inside and out, but they do not get the disability part at all. And so, our training for the service providers really focuses on their working together to actually fully support entrepreneurs with disabilities. And our curriculum for the entrepreneurs with disabilities themselves was really to develop a comprehensive plan that would plan for not just their business needs or their disability needs but both together.

ALICE: And after these trainings, have you seen actual systemic change in terms of the way these organizations are either communicating or connecting with one another?

KATE: Oh yeah, for sure. A lot of people that entrepreneurs with disabilities exist, and they're looking for ways to do that better within their organizations. Some of the service provider participants from disability community agencies may have realized, "OK, you know, that's not something that we can do right now, that's not necessarily something we're prepared to do, or maybe that's something our organization just shouldn't be doing right now." And that's good 'cause one thing that we don't want is for people to offer a service that they can't actually provide or that's outside the mission of their organization. And then some of them are saying, "OK, well, that's something we wanna work towards in the future, but this is what we can do right now to make systemic change within our organization, that will hopefully lead to this in the future." And so, we're seeing a lot of creative thinking that we haven't seen before.

[lounge-y music break]

ALICE: Is there anything else you'd like to share with me about either the CEED Project or your research?

KATE: Yeah, we've got a lot of entrepreneurs that are really, really taking steps right now to start their own business. We also had some people who decided "Entrepreneurship's not gonna be for me right now." But one area that's also important is something called intrapreneurship: when someone basically is being an entrepreneur within an existing organization that they work for basically saying, "OK, I have an idea for how we can improve this organization that I'm currently embedded in." And I think that's another area that can be really instrumental in changing organizations from the inside out and being innovative.

Another thing that I should mention is that I've been doing a lot of work, as I mentioned, trying to inform policy and policy recommendations. I've been involved with the Chicago Mayor's Office for People with Disabilities looking at entrepreneurship and economic opportunity. I'm also on a financial inclusion task force.

One thing that we have on our CEED website is entrepreneur profiles. We'd love to include more profiles of entrepreneurs so people can put a face to it, so people know what folks are actually doing.

ALICE: Kate, thank you so much for talking with me today, and thank you for all that you do.

KATE: Oh, awesome! Thank you so much for having me! I had fun.

Wrap-up

[hip-hop]

♪ How far will they go
Oh yeah, yeah…. ♪

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes including text transcripts are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Rooshey and Kate's research on our website.

The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening, and see you on the Internets! Byeee!!

♪ Rock it to the blast off
Stop drop dance off ♪